



Lyme Disease Association, Inc.

PO Box 1438, Jackson, New Jersey 08527
888-366-6611 Lymeliter@aol.com 732-938-7215 (Fax)
LymeDiseaseAssociation.org

Lyme Disease Association Written Testimony 2/6/09 to Connecticut Public Health Committee

Co-Chairmen Harris & Ritter & Committee Members:

As background: Lyme Disease Association (LDA), a US Environmental Protection Agency PESP partner, is all-volunteer national non profit devoted to education, research, prevention & patient support, has 32 allied organizations nationwide and is registered in Connecticut & has Lyme Disease Association Eastern Connecticut Chapter, two supporter groups, and an affiliate, Time for Lyme, which partnered with LDA to open the endowed Lyme and Other Tick-Borne Diseases Research Center at Columbia University, the first center in the world to study chronic Lyme disease. LDA has hosted/spoken at many seminars in Connecticut including the University of New Haven Lyme Conferences in 2007 & 2008 and awarded *LymeAid 4 Kids* funds to families without insurance.

Two weeks ago, I was invited to be part of a 3-day focus group workshop on *Lyme Disease in the South* at the Centers for Disease Control & Prevention in Atlanta; GA. A researcher opened his talk saying the situation with Lyme is "not so bad," then proceeded to show graphs of case numbers in a few states to prove his assertion—including both CT and RI numbers. I pointed out that those examples were flawed, since both those states had changed reporting requirements which caused both states' number to drop or not rise in a manner consistent with prior reporting before the criteria were changed. Misinterpretation of data, unfortunately, can drive resources and focus on a disease; for example, an unknowledgeable observer looking at CT's current '08 Lyme numbers might think Lyme has been eradicated in CT, since '08 reported numbers in CDC's *Mortality & Morbidity Weekly Report* (MMWR, -2-09) for CT are zero to date.

According to CDC, from 1990 through 2007, Connecticut had 42,042 reported cases of Lyme disease. CDC states only 10% of cases that meet the CDC surveillance criteria are reported,ⁱ that means 420,420 Connecticut residents developed Lyme that met the surveillance criteria over 17 years. 2007 numbers showed a 71% increase in CT over 2006 numbers, and the Connecticut Agricultural Experiment Station *Summary of Tick Testing Results* estimates that in Connecticut, "the number of Lyme disease cases reported may represent only 10-20% of diagnosed cases."

Data is often used to marginalize Lyme patients' problems, so it is important that those who shape public policy and laws are able to have access to all the data, not just data which vested interest would like to use to contend Lyme is hard to get and easy to cure. So thanks for allowing me to testify favorably today on physician protection.

Two man-made sets of criteria greatly influence the ability of doctors to treat Lyme patients, the CDC surveillance criteria and the Infectious Diseases Society of America (IDSA) Lyme treatment guidelines. Despite CDC's warning on their website that surveillance case definitions establish uniform criteria for disease reporting and should not be used as: the sole criteria for establishing clinical diagnoses; determining the standard of care necessary for a particular patient; or setting guidelines for quality assurance, or providing standards for reimbursement; the majority of doctors are inappropriately using CDC surveillance criteria to diagnose and treat. Patients who do not meet the CDC surveillance criteria— in an endemic region, an EM rash (plus a required test in a non-endemic region), OR major system involvement plus positive blood work— must scramble to find physicians willing to risk making a clinical diagnosis for Lyme disease. Problems about who has Lyme are fueled by unreliable Lyme testingⁱⁱ and by the fact that less than 50% of people develop the classic bull's eye rash.ⁱⁱⁱ

Despite disclaimers that the 2006 IDSA Lyme treatment guidelines are only recommendations **against any long-term treatment for people who are chronically ill with Lyme; against entire classes of antibiotics; against alternative treatments; against some supplements; and against individual physician discretion in diagnosis and treatment**, actual experiences prove otherwise. That is why, to date, almost 40,000 people have signed an LDA petition opposing the IDSA treatment guidelines on humanitarian grounds. (see www.LymeDiseaseAssociation.org)

Due to a settlement with the CT Attorney General, the current guidelines are being reviewed by a newly constituted panel. All Lyme disease treating physicians who applied for a seat on the upcoming panel were denied one, based on

having a "conflict" if they made over \$10,000 treating Lyme disease. The IDSA has confused helping patients get better with 'real' competing conflicts such as interests in testing and vaccines, and relationships with insurers—a profile found in the original IDSA guidelines panel. It is like publishing a manual for fixing cars that is written by academics studying about cars rather than by mechanics who are constantly under the hood.

Our Lyme mechanics, the treating physicians, are given that academically produced manual and told it is a guideline for treatment, not law. However, when they do not follow that "guideline," they are scrutinized by their state medical boards, by infectious disease specialists in hospitals and by insurance companies. They may have sanctions placed on their licenses, hospital privileges revoked, may be removed from hospital posts, and may have insurance plan inclusion revoked if they do not march lockstep with IDSA. This has led to a scarcity of physicians and a "chilled" treatment climate nationwide, even worldwide, where Lyme is now found in about 65 countries. CA, CT, MI, NC, NJ, NY, OR, PA, TX, VA are some of the states where physicians who treat long-term have been investigated by state medical boards for treating outside the short term standard of care.

Another set of guidelines for Lyme which address early infection and chronic disease, provide a second standard of care. They are published by the International Lyme & Associated Diseases Society (ILADS), a professional medical and research organization,^{iv} and are ignored by IDSA and often not disclosed to patients as part of the principles of autonomy and informed consent. Both IDSA's & ILADS' guidelines have passed the inclusion requirements of being evidenced-based for acceptance on the National Guidelines Clearing House website (NGC) produced by the US Department of Human and Health Services.^v

Patients who are not diagnosed quickly or not treated appropriately sometimes become chronically ill. A study has shown that patients with Lyme disease suffer a degree of disability equal to that of patients with congestive heart failure.^{vi} Yet these patients, often multi-members of one family,^{vii} now have to travel many hours outside CT to find care for their Lyme disease. Patients do not have the resources nor the health to fight the vested interests stacked against them, which is why legislation is necessary since it ensures that treating doctors within the state **cannot be** prosecuted for unprofessional conduct just for providing any longer term treatment deemed necessary in the treating physician's clinical judgment.

Development of antibiotic resistance is a reason sometimes cited to withhold treatment, despite the fact that resistance often develops due to **under usage** rather than over usage of antibiotics to eradicate organisms. The Union of Concerned Scientists estimates that 70% of antibiotics in the U.S. are fed to healthy pigs, cows, and chickens to promote growth and prevent disease, and they are concerned quite concerned this may be a significant cause of resistant bacteria.^{viii} Recent studies have shown that resistant strains of bacteria most often develop in hospitals due to improper hygiene by medical personnel. Other diseases are allowed long-term treatment including tuberculosis, Q fever endocarditis, and even acne. It appears that with little outcry, animals can be fattened with antibiotics, health care workers can practice shoddy hygiene leading to resistant strains, acne sufferers can get years of treatment, but terribly sick Lyme disease patients are singled out to be left without treatment because of undocumented accusations of resistance due to actual medical treatment.

In closing, CT owes it to its patients and physicians to pass a doctor protection bill, a version of today's bill with some definitions and tightening of protective language, which will simply level the playing field by providing treating physicians with a measure of protection they are entitled to, since there are two standards of care. Doctors should not be penalized for following the standard which in their clinical experience best improves patient health.

i Meade, Paul, CDC, Herald News 5-4-04, Jessica Adler

ii P. Coulter et al, *J. Clin Microbiol.* 2005Oct.; 43(10): 5080-4 *Two Year Evaluation of Borrelia burgdorferi Culture and Supplemental Tests for Definitive Diagnosis of Lyme Disease.* *Lancet* 1990, *Journal of Clinical Investigation* 1994 & S. Schutzer et al, *JAMA* Vol 282, No. 20 *Borrelia Burgdorferi: Specific Immune Complexes in Acute Lyme Disease*, Nov. 24, '99

iii R. Smith et al *Annals of Internal Medicine* 2002;421:421-428, 477-479 ; A. Pachner *Reviews of Infectious Diseases*-Vol. II, supplement 6 - September-October 1989 *Neurologic Manifestations of Lyme Disease*, the new "Great Imitator"; J.M. Johnson, Ph.D., Chief, Public Health, NPS Ticks and Disease

iv Expert Review of Anti-infective therapy 2(1) Suppl. 2004

v <http://www.guideline.gov/>

vi Connecticut Agricultural Experiment Station. "Summary of Tick Testing Results for 2003." www.caes.state.ct.us.

vii CDC unpub. data presented in Congressional forum, Wall NJ Oct 1992 (Later pub. in Lyme Times)

viii http://www.ucsusa.org/food_and_environment/antibiotics_and_food/myths-and-realities